

HIV / AIDS

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AIDS, Rights and the Federal Role

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By Robert Pear

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DR. C. EVERETT KOOP, the Surgeon General of the United States, said recently that the purely scientific problems posed by the AIDS epidemic were probably less difficult than the social and ethical questions. Foremost among such issues are the civil rights of people who have been infected with the virus—people who may or may not come down with the deadly disease. Several members of Congress have offered bills that would restrict discrimination and guarantee the confidentiality of the results of tests for infection with the virus. But Reagan Administration officials told a Congressional subcommittee hearing last week that a new Federal law was not needed at this time because the states already had or were moving to adopt the necessary protections. Robert Pear, a reporter in the Washington bureau of The Times, discussed the bills with Representative Henry A. Waxman, a California Democrat who is a sponsor of the legislation, and Robert B. Helms, an Assistant Secretary of Health and Human Services.

WAXMAN

Clarify the Rules

Question. Why do you believe that it is necessary to enact a Federal law prohibiting discrimination against people infected with the AIDS virus?

Mr. Waxman. Every public health and medical expert who has testified before the subcommittee agreed that strong confidentiality and nondiscrimination protections are essential to a successful testing program. The Administration's own health officials have said the same thing. The issue is whether we are going to permit the success of an AIDS testing program to be undermined while we're waiting for the states to act. The Federal Government ought to clarify the ground rules so we can get the program under way.

Q. Does your bill permit discrimination in certain cases?

Mr. Waxman. We would not protect confidentiality or prohibit discrimination in employment or any other area where it would be necessary to protect the health of other people. We would allow the disclosure of a positive blood test indicating the infection, the HIV virus, to public health officials, to other health workers and to sexual contacts so that they can be tested and protect themselves.

Q. What do you think of the Administration's argument that your bill would create a burdensome Federal bureaucracy not used to protect the rights of people with any other disease or handicap?

Mr. Waxman. This disease is different from any other we've ever had. We need a strong Federal effort to fight against the AIDS epidemic.

Q. Dr. Otis R. Bowen, the Secretary of Health and Human Services, argues that since each state has different problems and the number of AIDS cases varies greatly from state to state, each state should establish its own regulations.

Mr. Waxman. Where the differences dictate that the states may want to handle issues like AIDS contact tracing differently, we ought to permit them discretion. However, testing with counseling ought to be available to everyone and people ought to be protected in terms of confidentiality and against unreasonable discrimination - not just because of the rights of the individuals, but also to make a testing program successful. In a state where such protections are not in place, I don't see that some of the individuals we most want to be tested will cooperate. We need to establish the atmosphere for full cooperation so that testing can be undertaken in a widespread and, we might say, routine way. . . . Not only will testing in a particular state be undermined without these protections written into law, but when word gets out about someone somewhere being discriminated against, I think that will be an inhibiting factor even in a state where these laws are in place.

HELMS

Give States a Chance

Question. Why do you believe a Federal law prohibiting discrimination against people infected with the AIDS virus is unnecessary?

Mr. Helms. We are dealing with something that has traditionally been a matter of state law. Another reason is that we think the states are doing some very innovative things using a variety of approaches to what is a real problem. We would admit this is a real problem. But we do think the states are dealing with it. And furthermore, not even the states think they have the right answers. We don't think the Federal Government necessarily has the right answer either. This is a perfect example of why we should look to states first before we jump in with a Federal solution.

Q. Do you think that a state should have the right not to enact such a law?

Mr. Helms. Yes, but the primary reason is that almost all of them either come under existing Federal law or have laws which could deal with a lot of these problems. In some cases, the courts and states are trying to interpret these laws - that's not all worked out yet. Whether new legislation is needed, I don't think it is obvious at this point.

Q. In his testimony to Congress, Dr. Bowen said, "Most states already have statutes pertaining to the confidentiality of public health information." Mr. Waxman said that only 29 states have such protections. Do you think 29 of the 50 is adequate?

Mr. Helms. I don't think I ever saw a figure about how many states had them. But there are certainly Federal rules about confidentiality of medical records, in the conditions for participation for Medicare. Now whether, as a practical matter, these are effective in all cases is a different matter, but they're certainly there.

Q. What do you think of the argument that if there is a breach in confidentiality or if there is discrimination, people will be afraid to be tested?

Mr. Helms. That is a real concern. But that's another reason for having different efforts in the states so we can look at what is effective and which laws tend to create an environment in which people are more willing to come in and be tested.

Q. If, after a year or two, some states have not enacted civil rights laws in this area, would it be appropriate for the Federal Government to do so?

Mr. Helms. We will keep the door open. If it really turns out to be more of a problem, the President's principles of federalism allow that in certain cases Federal legislation is appropriate.

Q. Secretary Bowen said that Mr. Waxman's bill would create a burdensome new bureaucracy. Why is that?

Mr. Helms. I think there were some requirements in the bill that we would have to have some Federal effort to monitor this thing. But we already have an Office for Civil Rights with authority to monitor some of these problems now. And it is involved in investigating the complaints that come in under the existing Federal programs.